Age, Memory Loss and Perceptions of Dementia in South Asian Ethnic Minorities

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Abstract

Background: South Asian older adults are represented less frequently in mainstream mental health services or those for people with dementia. The aim of this study was to explore in detail the perceptions of dementia (symptoms, causes, consequences, treatments) held by South Asians and to discern how these understandings vary by age and by the self-recognition of memory problems, as these influence help-seeking behaviour.

Methods: Participants were allocated to three groups: younger adults; older adults; and older adults with memory problems. They completed the semi-structured Barts Explanatory Model Inventory for Dementia schedule, whilst older adults also completed measures of cognition (MMSE), and depression (GDS). Interviews were conducted in English, Gujarati or Urdu.

Results: Groups were similar in identifying unusual forgetting and confusion as the most frequent symptoms; stress and age as the most frequent causes; and talking to your GP/nurse, taking medication, and talking to family and friends as the most frequent treatments. Younger adults more often knew about risk factors and reported practical consequences more than older adults. Older adults with memory problems were more likely to describe sleep related problems or symptoms commonly associated with depression. They more often cited as causes of dementia lack of sleep, side effects of medication and medical reasons, and mentioned religion as a means to cope.

Conclusions: Findings highlight variability in perceptions of dementia across the South Asian Community and identify specific areas where dementia awareness could be raised in South Asian sub-groups to improve timely diagnosis, treatment outcomes and service access.

Keywords

Dementia, ethnic minority, explanatory models, illness representations, South Asians

Over the past few decades, the number of people from minority ethnic backgrounds in Western countries has increased significantly (ONS, 2011a; Tran et al., 2005; USCB, 2012). Amongst these groups, South Asians, including Indian, Pakistanis and Bangladeshis, represent one of the largest communities in the UK (ONS, 2011b). Reflecting the general trend of ageing societies, South Asians are increasingly affected by age-related diseases, such as dementia, and studies have suggested that they are under-represented in take up of health services for dementia and may delay seeking help (Nielsen et al., 2011; Mukadam et al., 2011). This may be related to barriers operating at: a patient, carer or community level; at a health professional level; or related to the structures and types of services available (Goldberg and Huxley, 1980; Giebel et al. 2015a; Mukadam et al. 2015). Given the importance of timely diagnosis and raising awareness of dementia (DH, 2009) improving access appears to require culture-specific approaches.

At a patient, carer or community level decisions on whether to seek help may be influenced by various factors including: perceptions of symptoms, causes, consequences and treatments held by individuals with dementia; and the common beliefs about illness held by their relatives and cultural group. These beliefs may not match the traditional model of illness defined by Western medicine. Exploring these explanatory models or 'common sense beliefs' may contribute to more culturally sensitive care (Bhui and Bhugra, 2002; Bhui *et al.,* 2006; Diefenbach and Leventhal, 1996; Kleinman et al., 1978). The Barts Explanatory Model Inventory-Checklist (BEMI-C) (Bhui et al., 2006; Rudell et al., 2009), was developed to assess cultural variations in explanatory models of common mental disorders for minority ethnic groups. This was adapted to create the Barts Explanatory Model Inventory for Dementia (BEMI-D) (Giebel et al., 2015b), designed specifically to explore explanatory models for dementia in South Asians.

Previous work has suggested that there are differences in understandings of the concept of dementia amongst South Asian older adults (Lawrence et al., 2011; Morhardt et al., 2010; Purandare et al., 2007). In a sample of younger and older Sikhs, a variety of conceptualisations of dementia were found, with many reporting never having experienced dementia within their community (Uppal et al., 2014). It has also been suggested that, in languages spoken by South Asians in the UK, the colloquial terms for dementia-related behaviours are generally interpreted as an insult (MacKenzie et al., 2005). Studies that have explored illness perceptions and knowledge of dementia amongst ethnic minorities have identified some common themes; and, where comparisons have been included, differences between those beliefs held by South Asians and other ethnic groups.

Several studies have suggested that knowledge of dementia is poorer in ethnic minorities in general, and specifically in South Asian groups (Cahill, et al., 2015). In Denmark, when compared with native Danish, Polish and Turkish immigrants, Pakistani immigrants were more likely to perceive Alzheimer's Disease as a normal part of ageing, or a form of insanity and had lower scores on basic knowledge of dementia and symptomatology (Rune Nielson and Waldemar, 2016). In the US, Ayalon and Arean (2004) found, when comparing Anglo, African American, Latino and Asian older adults, both Latino and Asian adults were more likely to hold stigmatizing views of Alzheimer's Disease and more often saw it as part of normal ageing. In the UK, Purandare et al. (2007) found that Indian older people had less basic knowledge of dementia and its epidemiology, when compared with white older people, and were less aware of personality, reasoning and speech being affected.

In South Asian groups, symptoms of dementia may be framed more often as part of physical health problems (Uppal et al., 2014; Mukadam et al., 2011). Symptoms of dementia were not always recognised (McCleary et al., 2012; Patel and Prince, 2001) and, indeed, individuals with dementia were sometimes seen as feigning a problem or changed behaviours were seen as intentional (Bowes and Wilkinson, 2003). Stigma was associated with a diagnosis of dementia (Bowes and Wilkinson, 2003; Turner et al., 2005) and memory problems were more often seen as a normal part of ageing (Rune Nielsen, 2016; Turner et al., 2005; Parveen et al., 2017; Johl et al., 2016; Jolley, D. et al., 2009).

Perceived causes of dementia were multiple, including: other medical conditions and medication (Bowes and Wilkinson, 2003; Adamson, 2001); changes and outside events, such as a visit to Pakistan, (Adamson, 2001; Bowes and Wilkinson, 2003); spiritual wrongdoing, blame for past actions or God's will (Mukadam et al., 2015; Turner et al., 2005; Adamson, 2001); lack of support, affection and care from family (Patel and Prince, 2001); and isolation and stress (Rune Nielson and Waldemar 2016; Uppal et al., 2014; Mukadam et al., 2015). Studies exploring beliefs about treatments for dementia also found a strong reliance on the family and self-help (La Fontaine et al., 2007; Mukadam et al., 2015); the belief that dementia was curable (Ruse Nielson and Waldemar, 2016) or, in contrast, that nothing could be done (Turner et al., 2005; La Fontaine et al., 2007).

Little is known about how these perceptions vary across age groups within the South Asian population in the UK or whether these perceptions have changed over time due to acculturation, which may have implications for future planning of services or public health campaigns. Purandare et al. (2007) found only a weak correlation between age and total Dementia knowledge scores, although the study involved only older people, and La Fontaine et al. (2007) found no differences in perceptions by age in a series of focus groups. In UK

studies of non-ethnic minorities, both Hudson et al. (2012) and Yeo et al. (2007) found no correlation between the age of respondents and dementia knowledge, although again the latter study involved only an older population. One study in Northern Ireland compared knowledge and attitudes across all age groups and found lower levels of knowledge of dementia and more paternalistic attitudes towards people with dementia in the older age group (McParland et al., 2012). This is in contrast with some overseas studies that found greater awareness of dementia and its risk factors in older and middle aged populations (Garvey et al., 2011; Riva et al., 2012; Arai et al., 2008).

Studies undertaken with people with dementia in the South Asian community exploring perceptions of the illness have often been qualitative, with small samples and often relied on the caregiver's perspective rather than that of the person with dementia. Harman and Clare (2006) identify the difficulties of understanding how illness representations develop in early stage dementia when the process of developing awareness itself may be impaired. However, understanding their perspective may be important in explaining low service uptake.

The present study employed the BEMI-D to explore perceptions of memory impairment and dementia symptoms, their causes, consequences and expectations of treatments amongst different sub-groups of South Asians - younger and older people and those with memory problems and those without - and to make quantitative comparisons across groups. To our knowledge this is the first study to explore differences in perceptions of dementia in these sub-groups. It was hypothesised that there would be a significant difference in perceptions between younger and older South Asians; and between South Asians with and without memory problems.

Method

Participants

Participants were recruited through two local community organisations in Greater Manchester and from two NHS Trusts. In the community organisations, staff approached current members and the wider public, so as to increase representativeness of the findings. Recruitment from NHS Trusts was via memory clinics and community services.

For participants to be eligible for the study, they had to fit into one of three groups: younger adults aged 30 to 59 years (Group A); older adults aged 60 years or older without memory problems (Group B); older adults aged 60 years or older with memory problems (Group C). Ethical approval was obtained from the NRES (Reference 11/NW/0858).

Materials

Barts Explanatory Model Inventory for Dementia (BEMI-D)

The BEMI-D was developed from the BEMI-C (Rudell et al., 2009) and is hierarchically structured with four over-arching checklists (symptoms, causes, consequences and treatments). Each checklist contains a series of themes (such as types of symptoms) and each theme includes a number of individual perceptions. Overall, the BEMI-D contains 197 perceptions. Further information on the process of adaptation is published elsewhere (Giebel et al., 2015b).

The administration of the BEMI-D varied slightly depending on respondents. Older adults with memory problems (Group C) were asked to relate symptoms, causes, consequences and treatments to their own experience. Participants without memory problems (Groups A and B) related the questions to someone known to them with memory problems or, for those with no such experience, to a vignette depicting the behaviour of someone with memory problems. Although the BEMI-D covers a variety of possible perceptions, the interviewer only questioned the participant about the over-arching checklist, such as '*Which symptoms do you associate with memory problems*?' Every answer given was then ticked on the list of perceptions under each theme, and any additional perceptions were recorded. If the participant struggled to name anything under a given checklist, the interviewer could cue for more detail, by naming a specific theme as an example. The full list of perceptions was not read out.

All participants were asked about demographic characteristics, including age; gender; ethnicity; religion; marital status; living situation; education; first language; ability to speak English; place of birth; age at migration (if appropriate); and number of years lived in the UK. Health information about diabetes, heart disease, difficulties with vision and mobility was also collected.

Standardised measures

In addition, older adults completed standardised measures of cognition - the Mini-Mental State Examination (MMSE) (Folstein et al., 1975); and depressive symptomatology – the Geriatric Depression Scale (GDS) (Sheikh and Yesavage, 1986).

Procedure

Interviews were undertaken by staff from two community organisations and also from DeNDRoN (Dementia and Neurodegenerative Disease Research Network) who attended a half-day training course in administering the tool and the standardised measures. Interviews took place either at the participant's home or at community centres and lasted approximately one hour. After written informed consent was obtained, the interviewers administered the BEMI-D schedule, questions about demographic characteristics, and for Group B and C only the MMSE and the GDS. The BEMI-D and all the scales were available in English, Gujarati and Urdu.

Data analysis

Frequency analyses of the demographic characteristics and the prevalence of individual perceptions mentioned across the three groups were undertaken. Independent t-tests and Chi-square tests were employed to explore significant variations in demographic characteristics and in clinical measures. ANOVAs were used for continuous demographic variables (age; age at migration; years lived in the UK) with Bonferroni post-hoc tests. The perceptions of the different groups were compared using Chi-square tests with adjusted residuals compared to capture specific differences. Data were analysed using SPSS Version 22 and significant values were set at $p<0.05$. For economy of presentation, in Tables 3, 4, 5 and 6 only those BEMI-D items differing by more than 20 per cent or statistically significant at the 5% level are shown. This cut-off was chosen as a face valid and legitimate tabular presentation of variance between the groups in an economical fashion (Giebel et al., 2016).

Results

Demographic and health characteristics

Table 1 shows the demographic characteristics across the three different groups and in the total sample. Group A was, as expected, significantly the youngest (Bonferroni $p_{A\&B}$=<0.001; $p_{A\&C}$=<0.001), the youngest at migration (if migrated) compared with Group C (Bonferroni $p_{A\&C}$=0.040), and had lived on average significantly fewer years in the UK than both older adult groups (Bonferroni $p_{A\&B}$=<0.001; $p_{A\&C}$=<0.001). Groups A and B comprised significantly more females than males, with Group C having a more equal gender distribution. For the total sample, the country of origin was similar divided equally between Indian and Pakistani backgrounds. Across the groups however, more members of Groups A and C were from Pakistan, whilst more members from Group B were from India. This significant variation was mirrored in religion, place of birth and first language. The ability to speak English was

significantly lower in Group C, whilst fewer members of this group had experienced higher education. Most participants were married and lived either with their family or their spouse, whilst significantly more members of Group C were neither married nor single (e.g. divorced or widowed) than Group A and significantly more of Group A lived with their family.

Comparing the two older groups, unsurprisingly Group B performed significantly better on the MMSE. They also had significantly lower depression ratings than members of Group C. The older age groups (B and C) had significantly higher numbers with diagnosed diabetes and heart disease and Group C had significantly higher numbers with mobility problems. The difference between the groups on the presence of diagnosed depression was not significant and occurrence low..

[INSERT HERE TABLE 1]

Common perceptions

The focus of analysis was upon differences in perceptions by age and by presence of memory problems. Nonetheless there were several items on each of the four subscales which were common and present across all groups. Table 2 reports the items mentioned by 50 per cent or more of at least one of the three groups. For symptoms – *unusual forgetting* was the most commonly cited across all the groups. *Confusion* was mentioned by over 50 per cent of the younger aged adults and the older aged adults without memory problems and nearly 50 per cent of those older adults with memory problems. *Repetition* was mentioned by over 50 per cent of the younger aged group.

The two most frequently mentioned causes across all three groups were: *stress, anxiety, worry or unhappiness;* and *your age*. In addition, 55 per cent of those older people with memory problems cited *medical reasons* as a cause.

There was less agreement across the groups in the consequences which they cited most frequently, with over 50 per cent of the younger adults (Group A) identifying *loss of skills, and/or functioning*; *impact on quality of life*; and *exposure to harm*. In contrast, for both older groups, no single consequence was mentioned by over 50 per cent. The consequence of *exposure to harm* was rarely cited (3%) by older people with memory problems.

Similar to symptoms and causes, for treatments there was marked agreement across the three groups in those items mentioned by over 50 per cent of group members. All three groups mentioned: *Talking to your GP/nurse; taking medication*; and *talking to your family or friends*. In addition, *socialising* was mentioned by over 50 per cent of younger adults.

[INSERT HERE TABLE 2]

Differences related to age

Table 3 shows the individual symptoms with most variation across the three groups. Younger adults mentioned the symptoms *not having insight into one's own condition*, and *repetition* more frequently than the older adults and *sleepiness* and *feeling lonely* less often.

When exploring differences in causal attribution by age (Table 4), younger adults cited *work problems (including retirement or lack of work), diet food intake or way of cooking; substance (ab)use (alcohol, tobacco, drugs, medications); accident, or bodily injury e.g. head injury;* and *heredity (genes)* significantly more often than older adults. They also mentioned *side effects of medication* less often than the older age groups.

[INSERT HERE TABLE 3 and 4]

There were age-related differences in perceptions of the consequences of dementia (Table 5). In particular, significantly more younger than older South Asians (Group B) identified as consequences of dementia: *loss of skills and/or functioning; difficulties in getting to places or keeping appointments; impact on quality of life; change of your role (in your family, community); changes in social life and relationships; misery caused to the person, their family, the people around them; losing your job or inability to work; losing your financial security; incontinence; exposure to harm; and changes in use and experience of public and private spac*e. Younger people cited *waiting for things to come back to memory* less often as a consequence.

Perceptions of treatments for dementia did not vary by age (Table 6).

[INSERT HERE TABLE 5 and 6]

Differences related to the presence of memory problems

For symptoms, older people with memory problems identified significantly more often: *having disturbed sleep*; *sleepiness; feeling lonely;* and *avoiding or not doing a lot of things* compared with the other two groups. They also identified less often: *disorientation*, *memory stuck back in time*, and *prefers to be alone or no social life*. Within the two older aged groups, there were differences in the reporting of *having disturbed sleep* with this cited as a symptom more frequently by those with memory problems.

Variations in perceptions of causes were also evident between those with memory problems and those without (Table 4). Group C cited *lack of sleep; side-effects of medication;* and *medical reasons* significantly more often than Groups A and B. Older people with memory problems also mentioned significantly less often: *Work problems; financial problems; diet, food intake or way of cooking; substance (ab)use (alcohol, tobacco, drugs and medications)* and *some accident or bodily injury (e.g. head injury)*.

The attribution of spiritual influences or fate as a cause was infrequent across the three groups. When all five spiritual/supernatural perceptions were combined (*Bad luck/can affect anyone at any time; fate/destiny; weakened spirit; given by God (e.g. as a test of faith or punishment);* and *supernatural influences (e.g. ancestors' spirit, jins, astrology)* there was no significant difference in occurrence across the three groups ($x^2 = 4.036$; $p = 0.133$).

Further differences were found between the older group with memory problems (Group C), and those without, in perceptions of consequences. Group C cited more frequently *using religion to cope* and *waiting for things to come back to memory* as adjustments made. They cited less often *misery caused to the person, their family, the people around*; and *exposure to harm* as consequences.

Variations in perceptions of treatment methods were also found (Table 6). Group C reported *accepting and dealing with fate* and *waiting for things to come back to memory* more frequently whilst using *relaxation/meditation* was reported less often. Although not reaching significance, the older group with memory problems (Group C) also reported *using formal support services/groups (e.g. day care centres, care homes) or talking to people with similar problems* less often than the other two groups.

Discussion

Despite some agreement in the most commonly cited perceptions of symptoms, causes and treatments across the groups, this exploratory study also found clear differences by age and presence of self-defined memory problems.

Common perceptions

The two symptoms most commonly mentioned by all groups were: *unusual forgetting* and *confusion*. However, only two thirds of older people identified *unusual forgetting* and around a third of younger adults and nearly half of both older age groups failed to mention *confusion* as symptoms. This suggests that despite current efforts to raise awareness of dementia more still needs to be done.

All three groups mentioned *stress, anxiety, worry or unhappiness* and *your age* as the two most common causes. In addition, over 50 per cent of the older people with memory problems cited *medical reasons*. This is similar to findings in the US in limited English proficiency communities, where stress, depression, life of hardship and trauma and old age were among the most commonly cited causes (Mordhardt et al., 2010). , In UK ethnic minorities, symptoms were attributed to physical illness (Mukadam et al. 2011) and social isolation or stress were seen as causes (Mukadam et al., 2015). Likewise, in a study of Asians in Goa, depression and dementia in later life were attributed to abuse, neglect or lack of love on the part of the children towards a parent (Patel and Prince, 2001). Causal attribution is important since it can influence attitudes to prevention, management of the condition and views on the individual's responsibility for their illness (Anderson et al., 2011). It can also influence help seeking (Hurt et al., 2011a; Sheikh and Furnham, 2000) with those attributing symptoms to social and psychological causes being more likely to be non-help seekers (Hurt et al., 2011a; Hamilton-West, et al., 2010).

The view of dementia as 'normal' ageing is a common theme in the literature in studies specifically with ethnic minorities (Johl et al., 2016) but also with the non-ethnic minority population (Clare et al., 2006). This study could not identify to what extent respondents who gave '*your age'* as a response were normalising dementia as part of the ageing process, or merely citing increased risk with age. This distinction is important since the former may impact on their help seeking behaviours. It has been suggested that older people with dementia may use this 'normalisation' of memory problems as a coping mechanism

(Lawrence et al., 2011; Gillies, 2000) and part of a self-maintaining response to diagnosis (Clare, 2003), but this study found it was highly cited across all the age groups.

All three groups cited: *talking to your GP*, *taking medication* and *talking to your family or friends* as the most common treatments. This bodes well for early recognition by primary care teams and by carers and friends, making primary care and public health campaigns important. In addition, over half of the younger people suggested socialising as a treatment, perhaps reflecting a belief that staying connected with others can be beneficial. Perhaps socialising also enables memories to be triggered by significant others, providing reassurance, and offering protection against the harmful effects of isolation (Shankar et al., 2013). Family reliance is evident in the literature with South Asians having: greater expectation of reciprocity across generations; more confidence in receiving this family support than counterparts in Black Caribbean or White British communities (Lawrence et al., 2011); and holding beliefs that individuals or families could make memory problems better (Mukadam et al., 2015; La Fontaine et al., 2007). Perhaps surprisingly, less than a third of all groups mentioned writing things down, using calendars and diaries as helpful strategies (Group A 18.1%; Group B 29.1%; Group C 9.1%). This is in contrast to some studies in the White European population which found that people with dementia identified practical coping strategies (Gillies, 2000; Clare et al., 2006) and may be particularly important since the belief that nothing can be done and a lack of control are associated with increased distress (Hurt et al., 2011b). Since such memory strategies are frequently employed in dementia care (Clarkson et al., 2017) it may be that some forms of non-pharmacological interventions are not reaching minority ethnic groups.

Differences related to age

Some significant differences in perceptions of dementia by age were found. The younger age group differed from the other two in more frequently identifying *not having insight* and *repetition* as symptoms of dementia. Overall, the main differences by age were in identification of the consequences of dementia or memory problems. Younger adults appeared to have greater awareness of the practical implications and losses associated with a diagnosis of dementia such as: *difficulties keeping appointments*; *changes in role in the family/community*; *exposure to harm*; and *loss of skills and/or functioning*. Some of their responses may also have reflected their stage in life by identifying impacts such as *losing your job* or your *financial security*. Overall these responses point to a more Westernised view held by the younger generation and greater knowledge of cognitive and behavioural features of dementia. This is possibly related to greater access to information, since

significantly more spoke fluent English and had completed higher education. A tendency for younger adults to have greater dementia knowledge was corroborated in a study of carers of people with mild cognitive impairment (Savla and Wang 2016).

A similar effect may have also been present in the differences in perceptions of causes of dementia, with the younger age group demonstrating greater awareness of risk factors: *diet and food intake*, *accident/head injury* or *heredity*. This is important since South Asians may have higher risk of vascular dementia for which there are preventable lifestyle factors (All Party Parliamentary Group on Dementia, 2013). In addition, the younger cohort often act as the gatekeepers to health services, influencing access for South Asian elders, with social pressure from significant others being a strong predictor of willingness to seek help (Hailstone, et al. 2016). These findings reinforce the need to consider the cohort effects across generations and to modify interventions to different groups, rather than presuming stability of ethnic identity (Iliffe and Manthorpe, 2004).

Differences related to the presence of memory problems

This study is rare in that it includes the perceptions of South Asian older people with memory problems. Understanding individuals' perceptions of their illness is important in gaining insight into their help-seeking behaviours and in providing acceptable and person centred care. Studies in the UK on illness representations of people with dementia from non-ethnic minority groups have suggested that their response lies on a continuum of self-maintaining responses, to maintain a prior sense of self, and self-adjusting, which involves acknowledging and integrating the changes into a new identity (Clare et al., 2016). Despite the similarities across the three groups on some core symptoms, causes and treatments, some significant differences between the older people with memory problems and the other two groups were evident.

Group C were less likely to identify *lack of insight* as a symptom, which given the nature of the illness is to be expected (Leicht et al., 2010). They were also more likely to mention symptoms associated with low mood state and sleep problems. One explanation for this is that the older people with memory problems in this study may have had undiagnosed depression, which may be related to their awareness of cognitive decline in the early stages of dementia or related to a biological cause associated with the presence of dementia itself (Korczyn and Halperin, 2009). It is also possible that a large proportion of Group C mentioned sleep issues due to their own experience, dementia being characterised by a disturbed circadian rhythm and sleeping pattern (Gehrman et al., 2005; Gibson et al., 2014).

This lack of distinction between symptoms is important because knowledge of Alzheimer's disease symptoms is associated with increased intention to seek help from professional sources (Weiner, 2003).

Older people with memory problems also differed from the other groups on some of the causes they identified, being more likely to cite *lack of sleep*, *side effects of medication* and *medical reasons* as causes of dementia or memory problems and less likely to identify the risk factors of dementia mentioned by the younger group. People from an Asian cultural background may also have more ambivalent attitudes towards Western medication than European or White counterparts (Horne et al., 2004; Kumar et al., 2008; Lawton et al., 2005) which may relate to their perception of causes, such as stress, as an alternative to a biological understanding of diseases (Kumar, et al., 2011).

On the consequences and treatment checklists, older people with memory problems also differed from the others in identifying items which were more concerned with their adaptation to and acceptance of their situation: *waiting for things to come back to memory* and *accepting and dealing with fate*. This sort of acceptance and passivity is not dissimilar to responses found in studies of non-ethnic minorities where older people with early-stage dementia gave consequences of 'taking things as they come' or 'can't complain' (Clare et al., 2006). Indeed, Matchwick et al. (2014) found that older adults with Alzheimer's disease developed pragmatic emotional responses to their situation. There are some indications that spirituality and religion may be beneficial in improving cognitive function, enhancing coping strategies and enabling more social interactions and better quality of life (Agli et al., 2015). In this study, whilst overall mention of any spiritual factors as a cause was low, the older people with memory problems mentioned *using religion to cope* as a consequence significantly more than the other two groups.

Although it did not reach significance, older people with memory problems were much less likely to mention the use of formal support services as treatments, such as day care centres and care homes, consistent with previous research (Bowes and Wilkinson, 2003). However, one concern must be that family capacity to provide support may reduce due to factors such as occupational mobility.

Limitations

This study has certain limitations. First, future research should adjust for level of education, ethnicity and religion in the older age groups, which was not feasible in this exploratory

study. Second, comparison of South Asians with the white British population would have been useful across all age groups, since previous studies have indicated lesser dementia knowledge in South Asians when compared with other ethnic minorities and the White population (Purandare et al., 2007; Turner et al., 2005). Third, no information was available on the numbers in Group A and B (those without memory problems) who had direct experience of someone with dementia, and how many used the vignette as a reference prior to the BEMI-D administration. Research has shown that knowledge of dementia is related to previous experience of having known or cared for someone with the condition (Low and Anstey, 2009). Recording this might have indicated the extent to which information was derived from the media or national dementia campaigns. Finally, it is possible that Group C, with many co-morbidities, consisted of people with both organic and functional causes of poor memory, such as higher levels of depression, which may influence the perceptions of dementia reported within this group, given the clear association between depression and poor memory (Dotson et al., 2008; Weaver Cargin et al., 2008).

Conclusions

Although all participants had similar understandings of common symptoms of dementia (such as forgetting and confusion), perceptions of associated symptoms, causes, consequences and preferred treatments of dementia vary amongst South Asians in different circumstances and in different age cohorts. It is worth noting the breadth of beliefs generated by South Asians in this study. Of the 197 possible perceptions only two causes (*supernatural influences* and *poison*) had no mention by any group member. It would be helpful for further work to investigate whether the differentiated explanatory models are also present within other groups. Understanding these variations in perceptions of dementia is important in order to provide more targeted information and interventions (Clare et al., 2016) and identify those older adults at greater risk of distress (Hurt et al., 2011b).

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Table 1: Demographic characteristics across groups

	Group A (N=72)	Group B (N=55)	Group C (N=33)	Total (N=160)	X^2 Test/ ANOVA	p-value
Age, *Mean (SD)*	44 (9.9)	70 (6.8)	73 (7.5)	60 (16)	F(2,115)=158.2	.000
Gender						
Male	30 (41.7)	23 (41.8)	18 (54.5)	71 (44.4)	1.743	.418
Ethnicity						
(British) Indian	31 (43.7)	42 (76.4)	6 (18.2)	79 (49.4)	32.393	.000
(British) Pakistani	39 (54.2)	13 (23.6)	27 (81.8)	79 (49.4)		
Religion						
Hindu	15 (20.8)	36 (65.5)	2 (6.1)	53 (33.1)	61.033	.000
Muslim	41 (56.9)	14 (25.5)	30 (90.9)	85 (53.1)		
Sikh	6 (8.3)	2 (3.6)	/	8 (5)		
Christian	9 (12.5)	/	/	9 (5.6)		
Marital status					12.052	.017
Single	6 (8.3)	/	/	6 (3.8)		
Married	60 (83.3)	45 (81.8)	24 (75)	129 (81.1)		
Other	6 (8.4)	10 (18.2)	8 (25)	24 (15)		
Living situation					16.318	.012
Living alone	2 (2.8)	4 (7.5)	3 (9.4)	9 (5.8)		
With spouse	11 (15.5)	23 (43.4)	9 (28.1)	43 (27.6)		
With family	57 (80.3)	25 (47.2)	19 (59.4)	101 (64.7)		
Other	1 (1.4)	1 (1.9)	1 (3.1)	3 (1.9)		
Education					24.278	.000
Primary/ none	4 (5.6)	6 (11.2)	10 (31.3)	20 (12.6)		
Secondary	18 (25)	19 (35.2)	15 (46.9)	52 (32.9)		
HE	50 (69.4)	29 (53.7)	7 (21.9)	86 (54.4)		
First language					64.800	.000
Gujarati	4 (5.6)	19 (35.2)	2 (6.3)	25 (15.8)		
Punjabi	24 (33.3)	14 (25.9)	6 (18.8)	44 (27.8)		
Hindi	7 (9.7)	7 (13)	2 (6.3)	16 (10.1)		
Urdu	13 (18.1)	10 (18.5)	22 (68.8)	45 (28.5)		
English	19 (26.4)	2 (3.7)	/	21 (13.3)		
Other	5 (6.9)	2 (3.7)	/	7 (4.4)		
English speaking						
Fluent	61 (92.4)	41 (74.5)	17 (53.1)	119 (77.8)	19.776	.000
Place of birth						
SA-India	26 (37.1)	33 (60)	7 (21.2)	66 (41.8)	52.308	.000
SA-Pakistan	23 (32.9)	10 (18.2)	24 (72.7)	57 (36.1)		
UK	16 (22.9)	/	/	16 (10.1)		
Other	5 (7.1)	12 (21.8)	2 (6.1)	19 (12)		
Age at migration, *Mean (SD)*	23 (9.6)	27 (11.5)	30 (16.1)	26 (12.1)	F(2,113)=3.354	.038
Years in the UK, *Mean (SD)*	23 (15.8)	41 (13.9)	41 (12.7)	34 (16.7)	F(2,124)=22.015	.000
MMSE	N/A	26.3 (3)	21.5 (5.7)		t(34.970)=4.175[1]	.000
GDS cut off (between 5 and 9)[2]	N/A	5 (9.4)	11 (35.5)		17.214	.000
Diabetes	10 (13.9)	19 (35.2)	18 (55)		19.11	.001
Heart disease	6 (8.5)	16 (29.6)	9 (27)		10.26	.010
Difficulties with vision	15 (21.1)	8 (15.1)	11(33)		4.36	.112
Difficulties with mobility	7 (9.9)	15 (27.8)	22 (67)		36.81	.001

Values are n (%), unless otherwise stated;
[1] t-tests for MMSE;
[2] Number of people (%) scoring above the cut off for depression, with a score of 5 or above indicating likely depression and a score of 10 or above almost always indicating depression.

Table 2: Commonly reported responses (Cited by 50% or more of at least one group)

	Group A (n=72)	Group B (n=55)	Group C (n=33)	Total
Symptoms				
Unusual forgetting	52 (72.2)	35 (63.6)	21 (63.6)	108 (67.5)
Confusion	44 (61.1)	30 (54.5)	16 (48.5)	90 (56.3)
Repetition	38 (52.8)	22 (40)	10 (30.3)	70 (43.8)
Causes				
Stress, anxiety, worry or unhappiness	50 (69.4)	34 (61.8)	18 (54.5)	102 (63.7)
Your age	45 (62.5)	38 (69.1)	24 (72.7)	107 (66.9)
Medical reasons	19 (26.4)	9 (16.4)	18 (54.5)	46 (28.7)
Consequences				
Loss of skills and/or functioning	44 (61.1)	18 (32.7)	11 (33.3)	73 (45.6)
Impact on Quality of life	41 (56.9)	16 (29.1)	14 (42.4)	71 (44.4)
Exposure to harm	40 (55.6)	20 (36.4)	1 (3.0)	61 (38.1)
Treatments				
Talking to your GP/nurse	50 (69.4)	35 (63.6)	27 (81.8)	112 (70)
Taking medication	49 (68.1)	29 (52.7)	25 (75)	103 (64.4)
Talking to your family or friends	45 (62.5)	33 (60)	21 (63.6)	99 (61.9)
Socialising	43 (59.7)	27 (49.1)	13 (39.4)	83 (51.9)

Values are n (%).

Table 3: Perceived symptoms

Symptom	Group A (N=72)	Group B (N=55)	Group C (N=33)	Percentage range	X^2	Significance levels, χ^2
Somatic/bodily symptoms						
Having disturbed sleep	23 (31.9)	4 (7.3)	15 (45.5)	38.2	17.7243	.000
Sleepiness	6 (8.3)	7 (12.7)	15 (45.5)	37.2	22.9201	.000
Mental symptoms						
Feeling Lonely	11 (15.3)	11 (20)	14 (42.4)	27.1	9.8635	.007
Disorientation	24 (33.3)	15 (27.3)	3 (9.1)	24.2	6.9147	.032
Not having insight into one's own condition	16 (22.2)	6 (10.9)	//	22.2	9.9929	.007
Memory stuck many years back in time	35 (48.6)	24 (43.6)	6 (18.2)	30.4	9.0016	.011
Behavioural symptoms						
Repetition	38 (52.8)	22 (40)	10 (30.3)	22.5	5.1235	.077
Avoiding or not doing a lot of things	12 (16.7)	6 (10.9)	12 (36.4)	25.5	9.1450	.010
Social life and relationships						
Prefers to be alone or no social life	29 (40.3)	20 (36.4)	6 (18.2)	22.1	5.0444	.080

Values are n (%).

Table 4: Perceived causes

Cause	Group A (N=72)	Group B (N=55)	Group C (N=33)	Percentage range	χ^2	Significance levels, χ^2
Social factors						
Work problems (including retirement or lack of work)	21 (29.2)	12 (21.8)	2 (6.1)	23.1	7.0694	.029
Financial problems or poverty	20 (27.8)	13 (23.6)	2 (6.1)	21.7	6.3970	.041
Culture/lifestyle						
Diet, food intake or way of cooking	23 (31.9)	13 (23.6)	1 (3.0)	28.9	10.6540	.005
Substance (ab)use (alcohol, tobacco, drugs, medications)	18 (25)	8 (14.5)	1 (3.0)	22.0	8.1105	.017
Lack of exercise	17 (23.6)	9 (16.4)	12 (36.4)	20.0	4.5570	.102
Physical health factors						
Lack of sleep	10 (13.9)	3 (5.5)	13 (39.4)	33.9	17.9930	.000
Some accident or bodily injury (e.g. head injury)	21 (29.2)	6 (10.9)	2 (6.1)	23.1	11.0817	.004
Side-effects of medication	8 (11.1)	7 (12.7)	15 (45.5)	34.4	19.5149	.000
Heredity (genes)	22 (30.6)	8 (14.5)	3 (9.1)	21.5	8.2605	.016
Medical reasons	19 (26.4)	9 (16.4)	18 (54.5)	38.1	15.0349	.001

Values are n (%).

Table 5: Perceived consequences

Consequence	Group A (N=72)	Group B (N=55)	Group C (N=33)	Percentage range	χ^2	Significance levels, χ^2
Skills, abilities & functioning						
Loss of skills and/or functioning	44 (61.1)	18 (32.7)	11 (33.3)	28.4	12.6578	.002
Taking a long time to complete work or sort out things	21 (29.2)	12 (21.8)	14 (42.4)	20.6	4.2241	.121
Difficulties in getting to places or keeping appointments	35 (48.6)	15 (27.3)	10 (30.3)	21.3	6.9764	.031
Mental/psychological well-being						
Impact on quality of life	41 (56.9)	16 (29.1)	14 (42.4)	27.8	9.8645	.007
Social life, roles and relationships						
Change of your role (in family, community)	31 (43.1)	12 (21.8)	5 (15.2)	27.9	11.0618	.004
Changes in social life and relationships	34 (47.2)	14 (25.5)	13 (39.4)	21.7	6.2915	.043
Misery caused to the person, their family, the people around	25 (34.7)	13 (23.6)	3 (9.1)	25.6	7.9741	.019
Financial security and well-being						
Losing your job or inability to work	28 (38.9)	11 (20)	3 (9.1)	29.8	12.0697	.002
Losing your financial security	27 (37.5)	9 (16.4)	1 (3.0)	34.5	17.2792	.000
Physical health and well-being						
Incontinence	15 (20.8)	4 (7.3)	2 (6.1)	14.7	6.8483	.033
Impact on behaviour/ Adjustments made for coping						
Waiting for things to come back to memory	4 (5.6)	5 (9.1)	9 (27.3)	21.7	11.0804	.004
Using religion to cope	11 (15.3)	5 (9.1)	12 (36.4)	27.3	11.0735	.004
Exposure to harm	40 (55.6)	20 (36.4)	1 (3.0)	52.6	26.5750	.000
Changes in use and experience of public/ private space	21 (29.2)	7 (12.7)	1 (3.0)	26.2	12.0619	.002

Values are n (%).

Table 6: Perceived treatments

Treatment	Group A (N=72)	Group B (N=55)	Group C (N=33)	Percentage range	X^2	Significance levels, X^2
Self/Psychological						
Accepting and dealing with fate	6 (8.3)	4 (7.3)	9 (27.3)	20.0	9.4526	.009
Self/Behavioural						
Waiting for things to come back to memory	6 (8.3)	4 (7.3)	12 (36.4)	29.1	17.9566	.000
Formal social support						
Using formal support services/groups (e.g. day care centres, care homes) or talking to people with similar problems	31 (43.1)	21 (38.2)	7 (21.2)	21.9	4.6999	.095
Spiritual/Alternative care						
Relaxation/Meditation	17 (23.6)	15 (27.3)	2 (6.1)	21.2	5.9818	.050

Values are n (%).